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Marie Préau, Virginie Villes, Francois Raffi, D Rey, Geneviève Chene, C Peronne, Jm Ragnaud, Catherine Leport, Bruno Spire

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Satisfaction with care in HIV-infected patients treated with long term follow-up antiretroviral therapy: the role of social vulnerability

M. Préau[1, 2, 4], V. Villes[2, 3,4], F. Raffi[5], D. Rey[6], G.Chêne[7], F. Marcellin [2,3,4] , C. Perronne[8], JM. Ragnaud[9], C. Leport[10], B. Spire [2,3,4]

and the ANRS CO8 APROCO-COPILOTE Study Group*

[1] LABECD Nantes University, France

[2] INSERM, U912 (SE4S), Marseilles, France

[3] Université Aix Marseille, IRD, UMR-S912, Marseilles, France

[4] ORS PACA, Observatoire Régional de la Santé Provence Alpes Côte d'Azur, Marseilles, France

[5] CHU Hôtel Dieu, Nantes

[6] CHRU, Hospices civils, Strasbourg

[7] INSERM U897, Université Victor Segalen, Bordeaux

[8] Hôpital Raymond Poincaré, Garches

[9] Hôpital Pellegrin, Bordeaux

[10] Université Paris-Diderot, Paris 7, UFR Medecine, AP-HP, site Bichat

Corresponding author: Dr Marie Préau, LabECD, Université de Nantes, chemin de la Censive du Tertre 44312 Nantes, France.

Tel: +33 4 40 14 13 04. Fax: +33 4 96 10 28 99.

Email: marie.preau@univ-nantes.fr

* The ANRS CO8 APROCO-COPILOTE Study Group:

Scientific Committee:

Steering Committee: Principal investigators: C. Leport, F. Raffi

Methodology: G. Chêne, R. Salamon

Social sciences: J-P. Moatti, J. Pierret, B. Spire

Virology: F. Brun-Vézinet, H. Fleury, B. Masquelier

Pharmacology: G. Peytavin, R. Garraffo

Other members: D. Costagliola, P. Dellamonica, C. Katlama, L. Meyer, D. Salmon, A. Sobel.

Events Validation Committee: L. Cuzin, M. Dupon, X. Duval, V. Le Moing, B. Marchou, T. May, P. Morlat, C. Rabaud, A. Waldner-Combernoux

Project coordination: P. Reboud

Clinical Research Group: V. Le Moing, C. Lewden

Clinical Centres (investigators): Amiens (Pr JL. Schmit), Angers (Dr JM. Chennebault), Belfort (Dr JP. Faller), Besançon (Pr JL. Dupond, Dr JM. Estavoyer, Dr Drobachef), Bobigny (Pr O. Bouchaud), Bordeaux (Pr M. Dupon, Pr Longy-Boursier, Pr P. Morlat, Pr JM. Ragnaud), Bourg-en-Bresse (Dr P. Granier), Brest (Pr M. Garré), Caen (Pr R. Verdon), Compiègne (Dr D. Merrien), Corbeil Essonnes (Dr A. Devidas), Créteil (Pr A. Sobel), Dijon (Pr P. Chavanet), Garches (Pr C. Perronne), Lagny (Dr P. Lagarde), Libourne (Dr J. Ceccaldi), Lyon (Pr C. Chidiac), Meaux (Dr C. Allard), Montpellier (Pr J. Reynes), Nancy (Pr T. May), Nantes (Pr F. Raffi), Nice (Pr JG Fuzibet, Pr P. Dellamonica), Orléans (Dr P. Arsac), Paris (Pr E. Bouvet, Pr F. Bricaire, Pr P. Bergmann, Pr J. Cabane, Dr J. Monsonego, Pr P.M. Girard, Pr L. Guillevin, Pr S. Herson, Pr C. Leport, Pr MC. Meyohas, Pr J.M.

Molina, Pr G. Pialoux, Pr D. Salmon), Poitiers (Pr F. Roblot), Reims (Pr C. Strady), Rennes (Pr C. Michelet), Saint-Etienne (Pr F. Lucht), Saint-Mandé (Pr T. Debord), Strasbourg (Pr D. Rey), Toulon (Dr JP. De Jaureguiberry), Toulouse (Pr B. Marchou), Tours (Pr P. Choutet).

Data monitoring and statistical analysis: J. Appy, S. Boucherit, V. Bouteloup, C. Brunet-François, V. Caron, M.P. Carrieri, F. Couturier, J.L. Ecobichon, L. Hardel, P. Kurkdji, S. Martiren, M. Onanga, E. Pereira, M. Préau, C. Protopopescu, A. Taieb.

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Abstract

The aim of this study was to determine factors associated with complete satisfaction with the care provided (satisfaction with physicians and satisfaction with services and organization) among HIV-infected patients followed up in the French ANRS CO8 APROCO-COPILOTE cohort. Analyses focused on cross-sectional data collected during the ninth year of cohort follow-up. Satisfaction with care (Bredard & al, 2005), sociodemographic characteristics and behavioral data were collected using self-administered questionnaires, while clinical data were derived from medical records. Complete satisfaction with care was defined as being 100% satisfied. Two logistic regression models were used to identify predictors of (i) complete satisfaction with physicians (n=404) and (ii) complete satisfaction with services and organization (n=396). Sixteen percent of patients were completely satisfied with physicians while 15.9% were completely satisfied with services and organization. Being older and reporting fewer discomforting antiretroviral therapy (ART) side effects were factors independently associated with complete satisfaction with both physicians and services and organization. Strong support from friends and absence of hepatitis C (HCV) co-infection were independently associated with complete satisfaction with physicians, while strong support from one's family and comfortable housing conditions were independently associated with complete satisfaction with services and organization. Even after nine years of follow-up, social vulnerabilities still strongly influence HIV-infected patients' interactions with the health care system. Day-to-day experience with the disease, including perceived treatment side effects, appears to play a key role in the quality of these interactions. More attention should be given to patient satisfaction, especially for socially vulnerable patients, in order to avoid potentially detrimental consequences such as poor adherence to ART.

Introduction

Patient satisfaction with care, in other words, his/her evaluation about the quality of care, has become recognized as being an essential element in the definition of quality in health care. Satisfaction with care can be defined as the extent to which an individual's health care experiences match his or her expectations (Pascoe, 1983). It can be broadly thought of as referring to all relevant experiences and processes associated with health care delivery.

Evaluating the extent to which patients are satisfied with health care services has considerable clinical relevance. It provides an indication of the degree to which a service meets patients' needs and expectations, which may in turn influence patients' retention in care.

In addition, several studies have investigated patient satisfaction with specific care such as dental care (Lemay, Kretsedemas, & Graves, 2010), access to a pharmacy (Karunamoorthi, Rajalakshmi, Babu, & Yohannes, 2009) or access to HIV screening (Brown et al., 2008).

Among cancer and other chronic diseases, evidence has also emerged that satisfaction with care is related to patients' compliance with medical recommendations and adherence to treatment (Borras et al., 2001), as well as improvement in one's health status (Guldvog, 1999).

In the context of research into HIV infection over the past several years, priority has centered more on adherence than on patient satisfaction with care or with physicians.

In clinical study, results of three open-label clinical trials have shown that PLWHA satisfaction is greater with abacavir (ABC)-containing triple nucleoside reverse transcriptase inhibitor (NRTI) highly active antiretroviral therapy (HAART) regimens than with protease inhibitors (PIs)-containing HAART regimens, and that patient satisfaction is significantly correlated with adherence to HAART (Jordan et al., 2005). Moreover, patient-provider relationships have been shown to have a crucial impact on patients' quality of life (QOL) (Préau et al., 2004). In addition, an analysis of temporal changes in patient-provider relationships during a five-year period after ART initiation has underlined the important role of the patient's self-perceived well-being and physician communication with patients in the occurrence of breaks of trust (Preau et al., 2008).

Another study exploring the connections between PLWHA adherence to HAART and their beliefs about and satisfaction with their primary care physicians (Roberts, 2002), showed that good patient-provider relationships tended to promote improved adherence.

Continuing with the context of primary care, a longitudinal multicenter urban study conducted in the US (Sullivan, Stein, Savetsky, & Samet, 2000) showed greater satisfaction with primary care physicians among those PLWHA who reported to be more comfortable discussing personal issues with their physicians, and who perceived the latter as being more empathetic and more knowledgeable in terms of HIV, even after adjustment for characteristics of patients and primary care.

Despite these studies, little is known about structural factors (such as an individual's living environment or his/her struggle to enter into the health care arena) which may influence PLWHA satisfaction in the context of the increasingly important role of hospitals in external follow-up. In addition, while patient satisfaction has generally been measured by evaluating the quality of the patient-provider relationship, the domain of satisfaction with care, specifically in terms of services and medical organization, requires greater exploration. This is justified considering that patients tend to be followed-up by several physicians.

The aim of this study was to investigate factors associated with PLWHAs' satisfaction with care, considering satisfaction with physician and satisfaction with services and medical organization separately.

Methods

Data Collection

The French APROCO-COPILOTE (ANRS CO-8) cohort was designed to study the clinical, immunological, virological and socio-behavioral course of HIV-1 positive individuals who started a PI-containing ART regimen (Préau et al., 2004). Patient HIV history was collected at entry in the cohort. Clinical and biological data were collected every 4 months thereafter by the treating physician. Psychosocial and behavioral data were collected using self-administered questionnaires first administered at patient entry into the cohort, then 4 months later, then every 8 months during the first five years of follow-up, and every 12 months thereafter. The present study focuses on cross-sectional data collected during the ninth year of follow-up. The questionnaire collected socio-demographic data, information about patients' satisfaction with care, data related to HIV transmission group (intravenous drug use (IDU), homosexual intercourse, heterosexual intercourse or other), QOL, social support, depressive symptoms, adherence to ART and self-reported side effects.

The self-administered questionnaire was given to the PLWHA during a medical visit and completed at the care site or at home. Each questionnaire was distributed inside an envelope in order to limit desirability bias.

Variables

Satisfaction with care: The French version of the self-administered questionnaire included 11 items about patient satisfaction with physicians and 9 items about their satisfaction with services and organization (Bredart, Bottomley et al., 2005; Bredart, Mignot et al., 2005). Complete satisfaction with care was defined as reporting to be 100% satisfied. A patient was considered satisfied overall if he/she reported a score between 80% and 99% for each of the 4 domains of satisfaction with physicians and for each of the 3 domains of satisfaction with services and organization, respectively.

Self-reported side effects: The self-administered questionnaire included a 29-item scale asking whether patients had experienced, at least once during the previous 4 weeks, any short-term treatment-related side effects (Justice et al., 2001).

Quality of life measurement: The self-administered questionnaire contained the 36-item WHOQOL-HIV scale (Leplege, Reveillere, Ecosse, Caria, & Riviere, 2000; O'Connell, Skevington, & Saxena, 2003; Skevington, Bradshaw, & Saxena, 1999). This particular QOL scale, developed by the WHOQOL Group (1998) ("Development of the World Health Organization WHOQOL-BREF quality of life assessment. The WHOQOL Group", 1998) was chosen as it is able to accurately reflect the problems of HIV-infected patients in the context of HAART. It assesses the following six QOL dimensions: physical QOL, psychological QOL, environmental QOL, level of independence, QOL concerning social relationship aspects and spirituality.

Adherence to ART: Following the methodology established by the AIDS Clinical Trial Group (Chesney et al., 2000) five questions were used to assess adherence to ART. Individuals were first asked to list, for each drug included in their ART regimen, the number of pills they had actually taken on each of the 4 days before the visit. Individuals were classified as highly adherent if they reported having taken 100% of their declared prescribed dose in the previous 4 days or if they reported to have completely followed their ART prescriptions.

Social support: Three questions, using 4-point scales (none, a little, quite a lot, a lot), were used to assess patients' perceived social support, respectively, from their main partner, family members and friends.

Housing conditions: A 4-point Likert scale was used to define the degree of comfort of one's housing (not at all, a little, quite or very comfortable).

Depressive symptoms: The questionnaire also included the complete validated French version of the Centre for Epidemiologic Studies depression scale (CES-D) (Fuhrer & Rouillon, 1989; Radloff, 1977). In the present analyses, patients obtaining a CES-D score higher than 17 for men and 23 for women were defined as having depressive symptoms.

Social vulnerability

Social vulnerability concerns a combination of characteristics related to financial conditions of one's life, evaluated by housing conditions and also social support for patients (from friends and family). In the context of French HIV infection and the APROCO COPILOTE cohort, housing conditions were shown to represent a pertinent indicator of financial difficulties (Bouhnik, 2002) and a lack of social support was shown to represent patients without a social network (Bouhnik, 2005 : Préau, 2004).

Statistical analysis

Two logistic regression models were used to identify respectively predictors of complete satisfaction with physicians and complete satisfaction with services and organization. In order to carry out a sensitivity analysis, another two logistic regression models were performed to identify the determinants of reporting overall or complete satisfaction with physicians and/or with services and organization. Variables associated with a p-value lower than 0.25 in the univariate analyses were considered eligible for inclusion in the multivariate model. A backward elimination approach based on the log-likelihood ratio test was used to identify the best set of independent correlates of the outcomes (significance threshold $p<0.05$). Finally, correlations between satisfaction with HIV care and both QOL and adherence to ART were assessed using Pearson correlation coefficients. All the analyses were performed using Stata 10.0.

Results

Patients selected:

Among the 620 patients followed up in the ninth follow-up year of the cohort, 410 responded to the self-administered questionnaire provided in that year, of whom 404 and 396 patients answered items related to their satisfaction with physicians and with services/organization respectively. Those who filled-out this self-administered questionnaire were less likely to be ART naïve at baseline than non-respondents (p = 0.004), and were also less likely to be born outside the European Union (p <10-3).

Among the 404 respondents to items related to satisfaction with physicians, a total of 63 PLWHA (15.6%) reported complete satisfaction and another 130 (32.2%) declared overall satisfaction. Among the 396 respondents to items related to satisfaction with services/organization, 63 PLWHA (15.9%) reported complete satisfaction and 128 PLWHA (32.3%) reported overall satisfaction.

Correlates of complete satisfaction with physician:

In the univariate analyses the following factors were all significantly associated with complete satisfaction with one's physician: older age, having been infected with HIV through sexual contact, not being co-infected with hepatitis C virus (HCV), reporting very comfortable housing conditions, strong support from friends and a lower number of side effects causing discomfort (Table 2).

The multivariate model (Table 1) confirmed that older age, strong support from friends, absence of HCV co-infection and a lower number of self-reported side effects causing discomfort were all independent correlates of complete satisfaction with one's physician.

Correlates of complete satisfaction with services and organization:

Univariate analyses for correlates of complete satisfaction with services and organization showed that older individuals, individuals infected through homosexual or heterosexual contact, those having very comfortable housing conditions and those receiving strong family support were all significantly more likely to be completely satisfied with services and organization (Table 3). PLWHA diagnosed HIV positive more recently were also significantly more likely to be completely satisfied with services and organization.

The multivariate model (Table 3) confirmed that older age, comfortable housing conditions, strong family support and a lower number of self-reported side effects causing discomfort were all independent correlates of complete satisfaction with services and organization.

Correlation with QOL and adherence to ART:

Adherence to ART and all QOL dimensions were significantly correlated with complete satisfaction with both physicians and with services and organization.

Analysis of overall or complete satisfaction with care:

The determinants of both "overall" (between 80% and 99%) and "complete" (100%) satisfaction with physicians and/or with services and organization were similar to those identified in multivariate analyses for complete (100%) satisfaction alone (results not shown, available on request).

Discussion

Firstly, our results show that a large majority of PLWHA participating in the French ANRS CO8 APROCO-COPILOTE cohort reported a high level of satisfaction with both physicians and medical organization after nine years of follow-up.

As previously shown (Sullivan, Stein, Savetsky, & Samet, 2000), satisfaction with care and more precisely with one's physician and institution is not associated with the patient's sociodemographic characteristics (with the exception of age), after adjusting for time since HIV diagnosis. We may hypothesize that older PLWHA have long term experience of the medical system, medical organization and medical norms. In addition, in the course of time, patients with chronic illness acquire skills to increase their ability to manage their disease (Bury, 1991, , 1997; Villaire & Mayer, 2007). Moreover, physicians treating older patients probably have a stronger tendency to empower patient self-management. Such empowerment can be created by structuring patient-physician interactions to identify problems from the patient's perspective, making office environment changes which remove barriers to self-management, and providing education both at an individual level and through available community self-management resources (Coleman & Newton, 2005). In the literature, it has been shown that patient perceptions of health care interactions vary according to age. A greater understanding of how and why age is associated with patient-provider communication could be useful in the design of interventions which enhance services at the doctor's office-level. Developing national policies to improve health care delivery and health outcomes would also be invaluable (DeVoe, Wallace, & Fryer, 2009). Moreover, older patients are

more capable of developing efficient patient-provider communication and thanks to better management of their illness they have a greater tendency to be satisfied with their physician and the medical organization. For example, one study has shown that older patients prefer a more active role in decision-making and are more engaged in the communication process during encounters with their providers (Kumar et al., 2010). Other studies have shown that younger patients are more critical of their healthcare provider's communication skills (Street, 2002) even though they are more satisfied with the medical follow-up as a whole (Hall & Dornan, 1990).

With respect to behavioral characteristics, it is clear that adherence to ART and satisfaction with HIV care are strongly associated, but it seems impossible to understand the causal pathways of this relationship.

Our results show the importance of social vulnerability. This point indicates that satisfaction with HIV care may reflect more the psychological state of patients needing help rather than being an indicator of the quality of care in itself. This in turn underlines the fact that access to care needs to be considered not only in terms of direct access by consultation but also in terms of patients' subjective health status and their role in patient-provider relationships. In France, access to care is free and open to all. Objectively however, it is not sufficient to simply consult a physician in order to enter into the process of care or to be assured good follow up. Social vulnerability represents a significant barrier to the building of a satisfying patient-physician relationship, notably because of widespread pre-existing representations and beliefs among both physicians and PLWHA.

As previously shown, social support appears to be associated with satisfaction with care (Tsasis, Tsoukas, & Deutsch, 2000). This result indicates that patients who have the opportunity to talk about their HIV infection and those who are socially well-inserted are more able to develop a satisfying relationship with their physician. On the contrary, patients without social support from family or friends have probably greater needs in terms of social support by physicians and the organization of care. Consequently, if these needs are not satisfied, they are more frequently unsatisfied with physician and with organization of care.

Finally, results show that patients reporting less side effects causing discomfort are more satisfied with both physicians and the organization of care. More than a physician dominated patient-provider relationship, this result regards both the physician's ability to actively listen to patients' perceptions of ART side-effects and to openly discuss them together (Preau et al., 2008).

Concerning HIV transmission group, it appears that patients infected by drug use are less satisfied in comparison with those infected through sexual contact. As others have previously observed for other chronic diseases, providers' beliefs and attitudes to IDU patients could impact the patient-provider relationship. Direct and indirect medical complications of drug use (Preau et al., 2008), drug dependence and the relationship of these patients with medical organisations and physicians may all affect satisfaction. It seems possible that these patients have different needs than simply those related to the follow-up of HIV infection, and it is not possible for physicians and medical teams to respond to such needs.

Some limitations have to be acknowledged. First, those patients who agreed to enroll in the cohort may have had better follow-up and greater overall satisfaction with care than the others. Second, patients who were lost to follow-up or who died before the 9th year of follow-up were not included in the present analysis.

Despite these limitations, the results underline that one subpopulation of PLWHA is particularly vulnerable because of both their social life conditions and characteristics related to social isolation. This population presents social vulnerability, which is in turn an obstacle to both the building of a satisfying patient-provider relationship and satisfaction with the organization of care.

Given the current lack of knowledge about satisfaction with care among PLWHA, this study provides important information for future areas of investigation regarding this theme, specifically in terms of optimizing patient treatment and follow-up.

Such socially vulnerable patients should be given special attention by medical staff as dissatisfaction with care providers may have detrimental consequences, not only on aspects of interpersonal relationships but also on patients' socio-behavioral aspects, such as adherence to ART.

Conclusion

In the current context of the evaluation of global follow-up of patients, and due to the fact that social vulnerability represents an indicator of dissatisfaction with care, this characteristic could be used in the development of associated studies.

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Table 1. Characteristics of respondents (study sample, n=410) and non-respondents (n=210) to the self-reported questionnaire of the ninth year of follow-up

	Respondents (n=410)	Non-respondents (n=210)	p-value [a]
Mean age (SD), years (M0)	39 (9)	37 (9)	0.075
Gender			
Men	324 (79)	165 (79)	0.98
Women	86 (21)	45 (21)	
Born in EU			
No	83 (20)	73 (35)	$<10^{-3}$
Yes	327 (80)	137 (65)	
HIV transmission group			
Homosexual or heterosexual or other	357 (87)	176 (84)	0.32
IDU	53 (13)	34 (16)	
Secondary school certificate (M0)			
No	239 (64)	119 (64)	1.00
Yes	135 (36)	67 (36)	
HIV clinical stage (M0)			
A or B	320 (78)	159 (76)	0.69
C	90 (22)	51 (24)	
Mean CD4 (SD), cells/mm3	579 (303)	577 (315)	0.96
Undetectable viral load			
No	306 (75)	142 (68)	0.11
Yes	104 (25)	66 (32)	
ART naïve (M0)			
No	241 (59)	97 (46)	0.004
Yes	169 (41)	113 (54)	
Co-infected with Hepatitis C (M0)			
No	330 (82)	147 (75)	0.048
Yes	71 (18)	49 (25)	
Mean time since HIV+ diagnosis (SD), months (M0)	57 (51)	58 (54)	0.77
Mean time since first ART treatment (SD), months (M0)	17 (23)	18 (24)	0.56

Note: Values are n (%) unless otherwise indicated. SD = standard deviation; IDU = injecting drug use.
[a] Chi-square test (categorical variables) or Student t test (continuous variables).

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Response Referee(s)'

Satisfaction with care in HIV-infected patients treated with long term follow up antiretroviral therapy: the role of social vulnerability

Referee: 1
I only have four questions:

1. Does the use of new and improved questions (questionnaires) over time diminish or changes the meaning and original concept when evaluating this cohort?

The French APROCO-COPILOTE cohort was set up in 1997 to study clinical, immunological, virological and socio-behavioral characteristics in HIV-1-positive patients who were beginning a combination antiretroviral therapy that included a PI. At initiation of the cohort, aims of the self-administered questionnaire concerned data related to adherence, self-reported side effects and quality of life. The self-administered questionnaire contained the same questions at each visit, but after nine years of follow-up, it is believed that investigating other dimensions is relevant. Satisfaction with care, to take one example, has not yet been studied in the context of long term patient follow-up.
A sentence justifying the recent focus on satisfaction with care in the context of HIV infection has been added in the introduction section.

2. Could you define "socially vulnerable patients (by their financial status or place of residence; heath, age, or ability to communicate effectively; by their present HIV/AIDS status or all of these) ?" – Page 2, Abstract – next to last line.

Social vulnerability concerns a combination of characteristics related to financial conditions of in one's life, as evaluated by housing conditions and also social support of patients (friends and family). In the context of French HIV infection and the Aproco Copilote cohort, housing conditions have been shown to represent a pertinent indicator of financial difficulties (Bouhnik, 2002) and a lack of social support to represent patients without a social network (Bouhnik, 2005 : Préau, 2004).

3. Does "structural factors" refer to the individuals' environment or their struggle to enter into the health care arena or both? Page 4, 1st paragraph.

Structural factors refer to both the individuals' environment and their struggle to enter into the health care arena.
We added this clarification in the introduction section.

4. Adherence to ART: Are indicating that if a patient for example, did not take his/he meds properly 15 days before completing the questionnaire but did comply 4 days before - was considered or classified as "highly adherent?"
What are they considered the other days and is this an overall proper representation for adherence? Maybe I missed something and forgive me if I did.

To evaluate adherence in APROCO COPILOTE cohort, we used the methodology established by the AIDS Clinical Trial Group (Chesney, 2000). Studies that have validated this scale have shown that adherence during the previous 4 days is representative of adherence during the previous month (Chesney, 2000).

Referee: 2

This article presents cross-sectional data from an HIV cohort follow-up, with the aim of understanding which patient factors are associated with complete satisfaction with care. The article is generally well-written and the topic is of interest. My main comments would be that the methodology section needs to

be more explicit, and the discussion should point out what new knowledge this research brings to the field and what practical implications can be drawn from these results (detailed comments follow).

♣ Title: The authors mention the term “social vulnerability” in their title, but the discussion focuses on “social precarity”. The same term should be used both in title and text (and abstract).

We agree with the reviewer and we deleted the term precarity.

♣ The introduction is well documented, and the aim of the study is clear.

♣ The authors chose to focus on patients that were globally or completely satisfied with care, and do not provide information on those who are not satisfied, although important clues for service improvement could come out of these data. If these data are not presented, there should be a rationale addressed in the introduction.

Due to social desirability bias, it is possible that some patients who were unsatisfied with care and their physician reported moderate satisfaction. Consequently, it seems more appropriate to focus our analysis on highly satisfied patients and not on those moderately satisfied or highly unsatisfied.

♣ The methods section lacks important information. First of all, the authors should give an idea to the reader as to the local context of care (country, hospital, organization of care, etc.) provided to the patients filling out the questionnaires. Furthermore, some more specific information about how the data was collected would be useful. Were the questionnaire filled in by the patients at the care site (in this case there could be a desirability bias) or mailed to the patients? Were they only administered in French? How about allophone or illiterate patients, were they excluded from the study? Exactly what socio-demographic data was obtained (only items in Tables or were there additional items) ? The authors should provide a rationale for which socio-demographic characteristics they chose, in particular, because in their conclusions they link them to precariousness and social vulnerability. Regarding the satisfaction questionnaire: has it been validated (in general, but also in French)? What were the different items of these satisfaction questionnaires?

Patients were recruited in 47 French hospital departments specialized in HIV care. Self –administered questionnaires were filled in by the patients at the care site. In order to limit social desirability bias, the self administered questionnaires were distributed in an envelope to preserve anonymity.
At inclusion in APROCO COPILOTE cohort, patients provided some information about socio-demographic characteristics. After several publications based on this cohort, a selection of pertinent sociodemographic characteristics was used for all analyses. As previously explained, social vulnerability concerns a combination of characteristics related to financial conditions of one’s life, evaluated by housing conditions and also social support for patients (from friends and family). In the context of our cohort, housing conditions were shown to represent a pertinent indicator of financial difficulties (Bouhnik, 2002) and a lack of social support was shown to represent patients without a social network (Bouhnik, 2005 : Préau, 2004).
Concerning the context of follow up, because the French healthcare system guarantees free-of-charge access to care to all HIV-infected individuals, the APROCO COPILOTE cohort probably contains a higher proportion of underprivileged populations than other longitudinal studies in countries where such access is unavailable.

♣ Results: Were they any non-respondents? Did they differ in any way from the respondents?

We have reformulated the first sentences at the beginning of the results section as follows:

Among the 620 patients followed up in the ninth follow-up year of the cohort, 410 responded to the self-administered questionnaire provided in that year, of whom 404 and 396 patients answered items related to their satisfaction with physicians and with services/organization respectively. Those who filled-out this self-administered questionnaire were less likely to be ART naïve at baseline than non-respondents ($p = 0.004$), and were also less likely to be born outside the European Union ($p < 10^{-3}$).

♣ In the discussion, the authors mention that “satisfaction with care … is not associated with the patient’s sociodemographie characteristics, with the exception of age”. It is not clear from the introduction which sociodemographic characteristics were collected. Did the sociodemographic characteristics include ethnic group or immigrant status? (these patients are often less satisfied with care, and are often linked to inequalities in access to care).

Among the 410 participants in the study, 83 (20%) patients declared being born outside the European Union. The origin of patients was not associated with either of the two response variables (p=0.77 for satisfaction with one’s physician and p=0.77 for satisfaction with services and organization, in univariate analyses). Information about patients’ characteristics is available in Table 1.

♣ The authors should discuss one of the results: the link between HIV infection by sexual contact and higher patient satisfaction

We agree with the reviewer and we now discuss this result in the discussion section

♣ On page 8 of the discussion, the authors mention “social precarity” without any prior mention of this predicament. First of all, a clear definition of what the authors mean by this term, and what factors they consider relevant to precarity, should be include in the introduction. Secondly, the authors should bear in mind that the term precarity is not exactly equivalent to “précarité” in French. In most English dictionaries, precarity cannot be found and the translation would be “precariousness”. The term “precarity” is found in texts usually referring to working conditions in postindustrial societies, such as “Poverty and Precarity” by the catholic activist Dorothy Day (1952), and carries a number of socio-political connotations.

We agree with the reviewer that the term precarity is ambiguous and have deleted it, defining instead social vulnerability in the methods section.

♣ The discussion should point out what new knowledge is brought by this research, and how this should impact provision of services.

We have added a section about this aspect in the discussions section.

♣ References: page 12 and 13 seem to be a repeat of pages 10 and 11 and should be edited.
We have deleted repetition to references.